The last year has been an exciting one for the Defeat Dementia in Down’s Syndrome Research Group. Soon after the completion of the brain scanning study, we received funding to begin the next phase of our brain imaging work, with new researchers and collaborators joining us to help make this venture a success. We are also looking forward to the next stage of the eye scanning study, taking place later this year. But none of this important and innovative research would be possible without the dedication and enthusiasm of the people with Down’s Syndrome who take part in these studies. It is very clear to us that there is only one way that we as researchers and you the public can find the answers we need — Together.

To demonstrate this, we have made a film, entitled Together, showing why we are doing this work, and how our participants, their families and supporters are helping us. The filming took place at our Open Day in March, which celebrated World Down’s Syndrome Day. The event was a huge success, with people travelling from all over the country to find out about and contribute to the research that we are doing here in Cambridge. This only serves to emphasise how we are all working Together — without the generosity of the public, particularly that of people with Down’s Syndrome willing to give their time, this work would not be possible.

In this summer newsletter you will find more details about the open day, our new film, and also about the exciting research projects and collaborations we are embarking on.

If you have a general enquiry about our research, please email Tony Holland at aih1008@medschl.cam.ac.uk. As our research papers become published with open access, we will be sending out electronic copies so you can see how knowledge is advancing. If you would like to be added to our email list, please contact: dh-admin@medschl.cam.ac.uk

Thank you again,

Tony Holland
Emeritus Professor of Psychiatry
Cambridge Intellectual and Developmental Disabilities Research Group
Around 100 members of the public attended our Open Day on Sunday 20th March 2016 to hear about the results of our studies and the future directions in dementia in Down’s syndrome research. People with Down’s syndrome and their families travelled from as far as Surrey, Leicestershire, Warrington, Norfolk, Essex, Bedfordshire and London for the event. There was a great deal of interest in our work and it was good to see the engagement and interaction with our researchers.

The Down’s Syndrome Association talked to a steady stream of interested visitors throughout the afternoon. Their support with our ongoing research is crucial and we are grateful for their participation. Thank you to the catering students from Eddie’s, one of our collaborating organisations, for providing the delicious refreshments this year, and to the volunteers from ‘Artworks’ who gave their time on the day to run activities and help make the event so successful.

We received positive feedback, including this from one of our visitors with Down’s Syndrome who wrote, “I most definitely enjoyed myself with many interests.”

It was exciting to have our film Together screened at the Arts Picture House in Cambridge on 17th May, as part of Dementia Awareness Week. Colin at Little Dragon Films, James at Sky Larking Films, and some enthusiastic research participants have made this film possible. The aim of the film is to help people understand why we are doing this research, and to show that taking part in these studies can be fun and exciting for everyone involved.

But most importantly, we hope the film will help people to see that Together is the only way that we can defeat dementia in Down’s syndrome! Thank you to everyone who took part.

If you have received a paper copy of this newsletter, please find a DVD of Together enclosed. Otherwise, you can watch it on YouTube https://youtu.be/pB7iqWUXQ1M and please share it in your networks, to help promote our work and generate more views.
NiAD: An international study about dementia in Down’s Syndrome

In Autumn 2016, we will be embarking on a new brain scanning project called the ‘Neurodegeneration in Aging Down Syndrome’ study, or NiAD. We will be working together with researchers in the USA to collect data from over 200 people with Down's Syndrome, and also from some of their siblings. The Cambridge part of this project will be led by Dr. Shahid Zaman, who also worked on the amyloid brain scanning study that many of you took part in. The NiAD project will be similar to the first brain scanning study, but with some exciting new additions.

As well as looking at how amyloid builds up in the brain, the NiAD study will also look at another important protein called tau. Tau helps to stabilise brain cells (called neurons), but in Alzheimer’s disease it stops working and the faulty tau sticks together to form tangles. These tangles build up inside neurons and cause them to die. New technology is now available which will allow us to look at tau in the brain, just like we can look at amyloid. To do this, we inject a liquid into the blood that contains a small amount of a radioactive chemical. This radioactive chemical briefly sticks to the tau, and the PET scanner takes a picture of the radioactivity to help us to see where the tau tangles are in the brain. The radioactivity is then washed away naturally by the body.

We hope that this project will strengthen and add to the findings from our amyloid brain scanning study. The project is currently being reviewed by the research ethics committee, and we hope that it will be approved in time for the study to begin in October. This is also when the brand new state-of-the-art scanners at the Wolfson Brain Imaging Centre will be ready to use. Some new research staff have joined our group to help us run this study, including Dr. Concepcion Padilla. We would like to welcome Concepcion to the team, and we wish her the best of luck with her research! Let us know if you are interested in taking part in this study by contacting Concepcion.

Ruma has it new findings are on the way!

Here in Cambridge we work as a large team of researchers so we can investigate many different aspects of dementia in Down’s syndrome. Dr. Ruma Raha-Chowdhury, a principal investigator at the John Van Geest Centre for Brain Repair, is a part of this team. Using the blood samples that our participants have donated, Ruma is trying to find an early indication of whether someone will develop Alzheimer’s disease. Ruma’s work has focused on inflammation in the brain, and she is particularly interested in a protein called TREM2, which plays a role in the way white blood cells fight disease. Changes (called mutations) in this protein are known to increase the risk of developing Alzheimer’s disease in the general population.

Ruma is looking at TREM2 in the white blood cells of our study volunteers to see if the differences in the immune system that occur in Down’s syndrome are related to the increased risk for getting Alzheimer’s disease. Ruma is currently writing up all of her findings from the Down’s syndrome study in a paper. If you would like to read this paper once it is published, please request to join our email list using the details on the front page of this newsletter.
Thank you for your support

Many thanks to all of you who have already taken part in one or more of our studies. We really appreciate your time and effort helping us with this research. This work is only possible with your help - it is especially valuable if you are able to help us with different studies. Please pass on this newsletter and the film link to anyone else you feel would be interested in our work.

We would also like to thank everyone who has helped us complete this research, including many people with DS and their families and others who provided support. We would particularly like to acknowledge the Down’s Syndrome Association; Hft; SEPT NHS Trust; Homerton University NHS Trust; Mersey Care; Jenny Gurney at the Fynvola Foundation; Dorothy Pritchard from Warrington Mencap; The Quemby family from Down’s Syndrome OK; VOX; the staff at the Wellcome Trust Clinical Research Facility; the staff at the Wolfson Brain Imaging Centre; and those at the Herchel Smith Building. We are grateful to the MRC, the DSA, Baily Thomas Charitable Trust, the NIHR Cambridge Biomedical Research Centre, the Health Foundation, Stevenage Biomedical Catalyst, Alzheimer’s Research UK, and Addenbrooke’s Charitable Trust for financial support.

We are also part of an international study funded by NIH in the USA. We are grateful for this support which, together with additional support from the DSA and ARUK, is enabling this research to continue.

Carers - what are your views?

The views of family carers and supporters of people with Down’s Syndrome are vital for the planning and success of our research.

We are currently seeking carers’ and supporters’ views about the acceptability of possible drug trials in the future, and we would be very grateful if you could help us by completing our questionnaire.

If you have received a paper copy of this newsletter, please find the questionnaire enclosed. Alternatively you can complete the questionnaire on-line: https://www.surveymonkey.co.uk/r/8DY5J6S

Thank you.